

MASSACHUSETTS CANCER REGISTRY

Abstracting and Coding Manual For Hospitals

Fourth Edition

November 2001

**corresponding to NAACCR Data Exchange Record Layout
Versions 9 and 9.1 for diagnoses made in 2001 and 2002**

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The manual is posted electronically at www.state.ma.us/dph/bhsre/mcr/canreg.htm

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Abbreviations Repeated in this Manual

ACoS	American College of Surgeons
AJCC	American Joint Committee on Cancer
aka	also known as
BRM	biological response modifier
CDC	Centers for Disease Control and Prevention
CNS	Central Nervous System
COC	Commission on Cancer
CT	computed tomography scan
DPH	Massachusetts Department of Public Health
EOD	Extent of Disease (SEER)
ICD-O-2	World Health Organization's <i>International Classification of Diseases for Oncology, Second Edition</i>
ICD-O-3	World Health Organization's <i>International Classification of Diseases for Oncology, Third Edition</i>
MCR	Massachusetts Cancer Registry
MRI	magnetic resonance imaging
NAACCR	North American Association of Central Cancer Registries
NOS	not otherwise specified
PET	positron emission tomography scan
SEER	National Cancer Institute's Surveillance, Epidemiology and End Results program
TNM	staging system of the American Joint Committee on Cancer's <i>Cancer Staging Manual, Fifth Edition</i>

PREFACE TO THE FOURTH EDITION

This edition of the Massachusetts Cancer Registry *Abstracting and Coding Manual for Hospitals* is a revision of the Third Edition (published in 1999). It applies to cases diagnosed during 2001 and 2002 and corresponds, whenever possible, to the data standards for the North American Association of Central Cancer Registries' Data Exchange Record Layout Versions 9 and 9.1. [There are no differences between the physical *layouts* of Version 9 and 9.1 (i.e., where each data field is stored in a case record, and the overall record length); there are slight differences in a few data standards and field names between the two Versions, and the MCR is adopting the Version 9.1 standards now.]

The Massachusetts Cancer Registry (MCR) continues to strive for compatibility with coding and abstracting practices of the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) program, the Centers for Disease Control and Prevention's National Program of Cancer Registries (CDC/NPCR), the North American Association of Central Cancer Registries (NAACCR), and the American College of Surgeons (ACoS). Compatibility with these groups assures consistent coding and allows Massachusetts hospitals and the MCR to compare data with other states and the nation.

The Massachusetts Cancer Registry Cancer Information Management System (MCR-CIMS) has been revised to accommodate the changes in this manual. Vendors of software reporting programs have also been informed of these changes.

The codes in this edition are to be used for cases diagnosed between January 1, 2001 and December 31, 2002. Pre-2001 cases that have already been abstracted should not be re-coded. A copy of the Third Edition of this manual should be retained in each hospital registry for reference when pre-2001 diagnoses have to be abstracted.

If the Date of Diagnosis of a particular case is completely unknown, the year of diagnosis should be estimated and the case coded accordingly with the data standards of the estimated diagnosis year; if even the approximate year of diagnosis cannot be estimated, the case should be coded in accordance with the coding standards for the Date of First Contact. (For example, if your facility's first contact with a cancer patient is on March 1, 2001 *and you cannot estimate the year of diagnosis* for the case, code the case as if the diagnosis occurred during 2001, i.e., with ICD-O-3 and Summary Stage 2000 coding.)

The format of this manual has been designed for placement in a three-ring binder which will allow the MCR to update the text easily. As changes are made, updated replacement pages will be sent to all hospitals so that each copy of the *Manual* will remain consistent with current abstracting and coding procedures.

PREFACE cont.

The following is a summary of the **data fields that have been deleted, changed or added** since the previous edition of this *Manual*:

Table I

<u>Fields Deleted Since the Third Edition</u>	
These data fields are no longer collected by the MCR:	
Discharge Date	
Surgical Approach	
Surgical Margins	
<u>Fields Changed Since the Third Edition</u>	
<u>Data Field</u>	<u>Comments</u>
Sequence Number -- Hospital (p. 33)	New name for the sequence number we collect from you.
Date of First Contact (p. 39)	New name for the field "Date of Admission or First Contact".
Birthplace, Place of Death (p. 45, p. 182)	Some new codes for these fields (in Appendix B) have been added, and a few old codes are no longer valid.
Race (p. 53)	The single code to describe a patient's race has been expanded into five separate fields so that multiracial patients may be recorded. Some additional details for categories "Asian Indian" and "Other Asian" have been added from a SEER manual. Instructions for how to assign codes have expanded.
Primary Site Code (p. 71)	The change to ICD-O-3 coding has caused some changes in site coding rules for hematopoietic diseases.
Histologic Type ICD-O-2 (p. 79)	New name for the histologic type codes applicable to diagnoses made from 1992 through 2000.
Behavior Code ICD-O-2 (p. 84)	New name for the behavior codes applicable to diagnoses made from 1992 through 2000.
Grade/Differentiation/Immunophenotype Code (p. 89)	New name for Grade/Differentiation/Cell Origin Code.
Class of Case (p. 96)	Class 6 cases changed from analytic to nonanalytic (for diagnoses as of 2000) since the Third Edition was published.
EOD -- Tumor Size (p. 100)	New rules conforming to SEER standards, most importantly for melanomas; new name for Tumor Size.
SEER Summary Stage 1977 (p. 130)	New name for the codes derived from the Summary Staging scheme that applies to diagnoses made through 2000.

PREFACE cont.

Table I (cont.)

<u>Data Field</u>	<u>Comments</u>
Text -- Staging (p. 147)	New definition for this item, conforming to its standard use.
Date of First Course Treatment--COC (p. 152)	New collected item for the MCR. We used to generate the treatment start date by choosing the earliest treatment modality date reported. We will now simply collect this date from you.
Diagnostic, Staging, or Palliative Procedures (pp. 153-155)	New names for the fields that were called "non cancer-directed surgery".
Other Cancer-Directed Therapy (pp. 178-180)	Special rules for coding treatment for hematopoietic primaries have been added.
<u>Fields Added Since the Third Edition</u>	
Sequence Number -- Central (p. 35)	This field is not collected from you. It is generated at the MCR and used for running automated edits on cases.
Race 1, 2, 3, 4, 5 (pp. 55-59)	allow the coding of multiracial patients
Histologic Type ICD-O-3 (p. 79)	for diagnoses made in 2001 and thereafter
Behavior Code ICD-O-3 (p. 85)	for diagnoses made in 2001 and thereafter
ICD-O-3 Conversion Flag (p. 88)	New item , produced by you or your data system. This field describes any code conversions (automatic or manual) that were applied to produce the ICD-O-3 codes in a case report.
Institution Referred From, Institution Referred To (pp. 98, 99)	New items for the MCR, read-only on our system. These fields contain codes for other facilities that have been involved with a cancer patient.
SEER Summary Stage 2000 (p. 131)	for diagnoses made in 2001 and thereafter
Date Case Report Received (p. 183)	New item for the MCR, but it's not collected from reporting facilities. We will record the date on which we receive each new case report that is uploaded to our system.
EOD -- Extension, EOD -- Extension Prostate Pathology, EOD -- Lymph Node Involvement (pp. 144-145)	New optional, read-only fields. If your facility records SEER EOD staging, we will be able to look at these codes. They are not required at this time and will not be edited by us.
Staging Narrative fields: Physical Exam; X-Rays/Scans; Scopes; Lab Tests; Operative; Pathology (pp. 145-147)	These text fields hold summary information pertinent to understanding the case's diagnosis, workup and staging.

PREFACE cont.

The purpose of this manual is to establish common data standards governing the collection of cancer data by the MCR so as to ensure uniform reporting of statewide cancer statistics.

This manual is designed to be a working document that will change continually to reflect changes that occur in coding and data standards. The MCR welcomes your questions, comments and suggestions for this manual. Please direct these to:

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SECTION I - INTRODUCTION

Introductory Note

The Massachusetts Cancer Registry (MCR) was established by legislation -- Massachusetts General Law Chapter 111, Section 111b -- in July 1980. This bill authorized the Commissioner of Public Health to establish a statewide cancer incidence registry and mandatory reporting system. After a planning and approval period of approximately two years, the MCR began operations (within what became the Bureau of Health Statistics, Research and Evaluation) on January 1, 1982.

The purpose of the MCR is twofold: first, the Registry is designed to provide public information and statistical analyses of cancer incidence in Massachusetts; second, it is designed to serve as a resource for epidemiologic investigations of cancer in Massachusetts. The design and structure of the registry were developed based upon the experience of several other population-based registries in North America and Europe.

In the fall of 1994, the MCR was awarded a grant from the CDC under the National Cancer Registries Amendment Act to expand both the data set and the existing reporting requirements to include not only hospitals, but all health care facilities and practitioners. As a result, the regulations governing cancer reporting in Massachusetts (105 CMR 301.000) were amended on March 24, 1995 to expand the collected data set. These regulations were then further revised to expand the definition of those required to report cancer cases to include non-hospital reporting sources on October 6, 1995.

The MCR *Abstracting and Coding Manual for Hospitals* is designed to provide hospitals with abstracting and coding procedures pertaining to those data items contained in the MCR data set. In no way does this manual imply any restriction on the type or scope of information collected at the hospital level. Many hospitals, particularly those with ACoS-approved cancer programs, will collect a much larger data set. Facilities may choose to accession cases that are not reportable to the MCR, such as basal and squamous cell carcinomas of the skin.

Confidentiality

As stated previously, Chapter 111, Section 111B of the Massachusetts General Laws established the Cancer Registry within the Massachusetts Department of Public Health to record cases of malignant disease in Massachusetts residents. The Cancer Registry Regulations (at 105 CMR 301.040) stipulate that the identity of individual patients whose cases are reported to the MCR are to be held in the strictest confidence. Information concerning a particular individual, and any other information maintained by the MCR which, because of name, identifying number, mark, or description, can be readily associated with a particular individual shall not be released to or discussed with anyone other than authorized personnel at the reporting facility, unless prior informed consent is received from the patient or his/her guardian or legal representative.

Massachusetts General Law does provide [at 105 CMR 301.040(E)] for the release of MCR data by the Commissioner of Public Health, for research and statistical purposes, to the authorized representative of a study or research project sanctioned by the Commissioner under strict conditions guaranteed to maintain confidentiality. The Cancer Registry Regulations specifically prohibit the release of Social Security Number. The MCR also maintains confidentiality policies and procedures to protect information that could be used to identify data concerning a specific facility or physician.

Casefinding

Casefinding is the process of identifying reportable cases. It involves careful monitoring of records maintained by the departments that usually deal with cancer patients at your facility.

The primary sources for case identification include these records:

- pathology reports (histology, cytology, hematology, bone marrow, autopsy findings)
- disease indexes
- daily discharges
- outpatient records
- radiation therapy records
- oncology clinic records

The following should also be considered as additional sources for casefinding:

- surgery reports
- nuclear medicine logs and radiology logs (including logs of scans)

INTRODUCTION cont.

General Reporting Requirements

Hospitals must report all cancer cases diagnosed on or after January 1, 1982, whether first seen at their facility with evidence of cancer or for cancer-directed treatment. Cases diagnosed first at autopsy should also be reported. A report is required regardless of whether or not the patient was diagnosed elsewhere previously. A report is not required if the patient was first seen at the reporting hospital prior to January 1, 1982 and is admitted again after that date. Do not report recurrences. Massachusetts residents and non-residents (as well as residents of foreign countries) are to be reported.

Nonanalytic cases of Class 3, 4, and 9 *diagnosed during 1995 and thereafter* should be reported. Cases of Class 3, 4, and 9 *diagnosed before 1995* should not be reported. (Nonanalytic cases of Class 5 -- autopsy-only cases -- are reportable for any diagnosis year 1982 and thereafter.) Reporting cases of Class 6 to the MCR is optional; if a Class 6 case was *diagnosed before 1996*, it should not be reported.

Cases must be reported to the MCR within 180 days (six months) of the date of diagnosis for all analytic cases and autopsy-only cases (Classes 0, 1, 2, and 5). Cases of Classes 3, 4, 6, and 9 must be reported to the MCR within 180 days of your facility's date of first contact with the patient. (For example, if a patient was diagnosed January 1, 2001 but *your* facility had no contact with the patient until January 1, 2003 and the case is of Class 3 to you, then you are required to report the case to the MCR by July 1, 2003.)

See the **REPORTABILITY** section for details of reporting requirements.

INTRODUCTION cont.

Reporting Methods: Media and Formats

Cases should be reported to the MCR on floppy diskette (3.5-inch, IBM-formatted) in NAACCR Data Exchange Record Layout Versions 9 or 9.1. If this is impossible, cases may be reported on paper MCR Cancer Patient Abstracts, available from the MCR (telephone 617-624-5645). Paper submissions to the MCR must be printed legibly or typed.

For facilities employing the services of a software vendor for reporting cases, it is the *hospital's* responsibility to work with that vendor to ensure that the proper data fields are received at the MCR in the proper format. The MCR does not have contracts with software vendors and therefore cannot be involved in arrangements with them. This is the hospital's responsibility.

Changes to Previously Submitted Cases

With the passage of time, a patient's medical record becomes more complete with regard to information initially missing or uncertain. It is therefore established practice to accept the thinking and information about the case at the time of the latest submission, or the most complete or detailed information. Thus, there may be changes in the coding of primary site, histology, stage (at diagnosis), etc., as the information becomes more certain. The patient's birthdate, Social Security Number, or the spelling of his/her name might also be changed on your data system. The MCR must be made aware of such changes.

There may also be cases reported which later information indicates never were reportable diagnoses. The MCR must be notified so that these cases can be deleted from our system.

The MCR no longer accepts changes/deletes on paper forms. Also, do not send changes on diskette. If submitted in a batch of new cases on diskette, changes appear to our system as new cases and they must be processed fully before they can be identified as a "change form". This slows the MCR's case processing and inflates the reporting facility's duplicate case counts.

You should call the MCR at 617-624-5645 and report a change/delete over the telephone. Ask to speak to one of our cancer registrars, and have the patient's identifiers ready. Be sure to speak directly to a registrar, or leave a message that you'd like to be called back. Do not leave patient information on the MCR voice-mail system.

References

In addition to this manual, a hospital registry should have the following references for coding:

- *International Classification of Diseases for Oncology, Third Ed.* (World Health Organization, 2000; errata published May 2001) -- The "ICD-O-3" (purple) manual contains internationally recognized codes for different types of cancer and sites in the body where they occur. This edition is used for cases diagnosed in 2001 and later. The softcover version (subtitled *US Interim Version 2000*) differs slightly from the hardcover version, and portions of the May 2001 errata also apply to the softcover version. Be sure that your copy (hard or soft) is kept updated.
- *International Classification of Diseases for Oncology, Second Ed.* (World Health Organization, 1990) -- The "ICD-O-2" (green) manual is used for cases diagnosed between 1992 and 2000. After its publication, a few histology codes and a grade/cell origin code were added to the ICD-O-2 codes, and a topography code was deleted. Be sure that your copy was kept updated.
- *International Classification of Diseases for Oncology, First Ed.* (World Health Organization, 1976) -- "ICD-O" or "ICD-O-1" is used to code cases diagnosed before 1992. (Field trial editions of ICD-O-2 published 1986 - 1988 may be used for coding diagnoses between these years and 1991.)
- *SEER Summary Staging Manual 2000: Codes and Coding Instructions* (National Cancer Institute, 2001) -- This (red) book defines SEER Summary Stages and codes for diagnoses made in 2001 and thereafter. The manual appears on the SEER website at <http://seer.cancer.gov/Publications/SummaryStage>. Electronic versions of this book posted on the SEER website *before June 18, 2001* differ slightly from the final (hard-copy) version. Be sure that your copy is kept updated.
- *Summary Staging Guide for the Cancer Surveillance, Epidemiology and End Results Reporting (SEER) Program* (National Institutes of Health, 1977, last Revision 7/86) -- This staging guide defines SEER Summary Stages for diagnoses made between 1977 and 2000. The same material can also be found in the *SEER Self Instructional Manual for Tumor Registrars: Book 6*. This book may now be referred to as "SEER Summary Staging Guide 1977".
- *Cancer Staging Manual, Fifth Ed.* (American Joint Committee on Cancer, 1997; clarifications issued 1/22/99) - This manual contains definitions and explanations required for assigning TNM stages to cases diagnosed between 1998 and 2002. [The 4th Ed. (called *Manual for Staging of Cancer*) should be used to stage cases diagnosed between 1993 and 1997; the 3rd Ed. is for staging cases diagnosed 1989 - 1992; the 2nd Ed. is for cases diagnosed 1984 - 1988; the 1st Ed. is for cases diagnosed before 1988.]

INTRODUCTION cont.

- *Self Instructional Manual for Tumor Registrars, Book 8, Antineoplastic Drugs, Third Ed.* (SEER Program, National Institutes of Health, 1993). *Book 8* is THE standard source for coding drugs used in cancer treatment. SEER, the ACoS/COC and the NAACCR all refer to this manual for standardized drug coding.

The following references can be very helpful when abstracting and coding cases.

- *Self Instructional Manuals for Tumor Registrars* (SEER Program, National Institutes of Health)
 - Book 1. *Objectives and Functions of a Tumor Registry* (1999)
 - Book 2. *Cancer Characteristics and Selection of Cases* (1991)
 - Book 3. *Tumor Registrar Vocabulary - The Composition of Medical Terms* (1992)
 - Book 4. *Human Anatomy as Related to Tumor Function* (1995)
 - Book 5. *Abstracting a Medical Record: Patient Identification, History and Examinations* (1993)
 - Book 6. *Classification for Extent of Disease (Summary Staging Guide)* (1977)
 - Book 7. *Statistics and Epidemiology for Cancer Registries* (1994)
 - Book 8. *Antineoplastic Drugs* (1993) -- noted above
- *Standards of the Commission on Cancer Volume II: Registry Operations and Data Standards (ROADS)*. (American College of Surgeons, 1996, *Supplement* issued 1997; revisions dated 1/1/1998, 3/16/2000, 8/2000) -- This manual contains field definitions and codes recommended for use in hospitals with ACoS approved cancer programs. This replaced the *Data Acquisition Manual* (DAM). Keep your copy updated.
- *Standards for Cancer Registries, Volume II: Data Standards and Data Dictionary, Fifth Ed.* (North American Association of Central Cancer Registries, 2000) and *Sixth Ed.* (2001) -- These books describe the data fields and codes accepted in the NAACCR data exchange record layout Versions 9 (2001 diagnoses) and 9.1 (2002 diagnoses). It is useful for understanding why certain codes fail edits, which data fields are required (or only recommended) by different groups, how the coding of some fields has changed, and on which data items the standard-setting organizations still disagree.
- *The SEER Program Code Manual, Third Ed.* (SEER Program, National Institutes of Health, 1998). This book provides the data standards for recording cancer cases for SEER registries. It applies to diagnoses made as of January 1, 1988.
- *SEER Extent of Disease -- 1988, Codes and Coding Instructions, Third Ed.* (SEER Program, National Institutes of Health, 1998; errata/corrections issued July 2000). This book provides the codes and instructions for recording staging data in the SEER Extent of Disease system.

Abstracting Requirements for Nonanalytic Cases

Although the ACoS does not require hospitals to abstract nonanalytic cases, population-based cancer registries like the MCR must record all cases regardless of place of diagnosis or class of case. The MCR therefore requires that nonanalytic cases (of Classes 3, 4, 5 and 9) be abstracted and submitted to the MCR. Reporting cases of Class 6 (also now nonanalytic) is optional; *if* your facility collects Class 6 cases, you should report them to us. (See pages 96-97 for definitions of "Class of Case".)

Reporting requirements for cases included in Classes 3, 4, 6 and 9 are less stringent than those for other cases. The reporting hospital's medical record often does not contain all the required data, or contains only second-hand data. Report any information included in the medical record. It is not necessary to obtain *missing* information, although you may choose to do so.

Although a complete abstract is not required, certain data items must be completed in order for the case to be processed:

- Reporting Facility Code
- Medical Record Number or Accession Number
- Patient Name (Last, First, Middle)
- Address (preferably at the time of diagnosis; otherwise, for the current admission)
- Birth Date
- Age at Diagnosis
- Social Security Number
- Sex
- Race Codes
- Primary Site Code
- Laterality
- Histology/Behavior/Grade Codes
- Date of Diagnosis
- Sequence Number--Hospital
- Type of Reporting Source
- Date of Last Contact

Even though information for many required data fields might not be available, all of the fields must be filled in (i.e., not left empty). When necessary, enter the codes for UNKNOWN or NONE.